TESTIMONY

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Hearing of the United States Senate Cancer Coalition

National Cancer Legislative Advisory Committee Report

Conquering Cancer: A National Battle Plan to Eradicate Cancer in Our

Lifetime

October 10, 2001

The Honorable Dianne Feinstein The Honorable Sam Brownback Co-Chairs

Testimony before the Senate Cancer Coalition Amy S. Langer October 10, 2001

Thank you for the opportunity to join you and my colleagues to discuss the Delivery and Quality Care recommendations of the NCLAC report, *Conquering Cancer: A National Battle Plan to Eradicate Cancer in our Lifetime.* Today I will offer thoughts from the same perspectives I brought to our intensive and important NCLAC Committee efforts. I am a passionate advocate for the needs and concerns of people with cancer, an educator, the head of a 16-year old national non-profit breast cancer organization, and a breast cancer survivor. I plan to celebrate the 17th anniversary of my diagnosis later this month.

As the Executive Director of the National Alliance of Breast Cancer Organizations (NABCO), I am engaged in the fight against cancer, every day. Our organization educates the public, offers information, advocacy and guidance about the disease, and funds community programs that connect medically underserved women with education and services. Over my 14 years at NABCO, we have seen – and brought about – extraordinary progress in the fight against breast cancer. Deeply committed and working together, over the past decade our country's breast cancer patients, survivors and their families, citizens, clinicians, researchers, public heath professionals and policy makers have forever changed the face of breast cancer. Where there was stigma and shame, there is now empowerment and hope. Innovative public education programs coupled with increased screening have changed women's attitudes and behavior, shifting detection to earlier stages of disease. Expanded research budgets and the acceleration of discovery have produced better treatments, extending survival and offering millions the chance to carry on with their lives.

This is an exciting time of opportunity and promise, and with your help, the momentum of the past decade will continue – and it must continue. However, in order to achieve success, transformation and massive improvements are needed in our system for implementing local cancer education and services, in the delivery of quality cancer care, and in America's symptom-driven health culture.

NCLAC Goal 10: Collaborative State-Based Action Plans

As in any war, the war against cancer is fought on the ground, step by step. Those of us at work in cancer are more often covered in paper than in glory. Despite the exciting prospects of powerful "silver bullets" that unlock and disable cancer's code, these discoveries will be impotent if they cannot and do not reach all the people who need them -- regardless of means, culture or where they live. The best treatments will also fail if used too early or too late, in the wrong amount or sequence, or if not offered to patients who will benefit. A large part of our future success against cancer will flow from businesslike hard work -- work that results in a sensible local health infrastructure, timely communication, effective collaboration, and implementation of thoughtful strategic plans that reflect the needs of each community. When this in place, we will need to measure performance and assess outcomes, without the hindrance of multi-year reporting lags. Our state health departments, Indian Health Service, CDC, HRSA and NCI need guidance and resources to create an even more effective, coordinated local effort.

NCLAC Goal 11: Standards for Quality Cancer Care, and Surveillance

America offers some of the most sophisticated health care in the world, but its delivery to people with cancer is plagued by inconsistency, illogical variation, lack of clarity and outdated application. While we perfect how best to prevent, treat and cure all types of cancer, and alleviate the suffering it causes, we must attend to the adequacy of the delivery of the highest quality cancer care to every community in America. In this information age, consensus knowledge – especially that results from the government's investment in cancer research – can and must be disseminated broadly and promptly. This is a central mission of our Agency for Healthcare Research and Quality, and expanding its efforts in collaboration with the cancer community must be part of our commitment.

NCLAC Goal 12: Implement a National Cancer Prevention Initiative

In the field of medicine, it is clearly unconscionable and unethical to withhold known methods to prevent or cure disease, or to intentionally hamper recovery. If we are serious about beating cancer, it is time for America's leaders to assume this same responsibility, starting with the known causes of cancer and the certain ways to prevent it. There is no longer any credible reason not to give the FDA and others the resources and broad authority to protect America from cancer-causing tobacco products. We also must offer every person the chance to improve nutrition and increase physical activity -- two powerful tools against cancer. We must educate, inform, and encourage our country to evolve from current symptom-driven health behavior to a culture of "wellness," where each of us embraces our responsibility for staying well.

This may seem like unexciting stuff, less appealing than the puzzle of research or the promise of the next cure. But at the end of the day, cancer threatens each of us in our homes and in our communities, and we must face this adversary with practical as well as transformative approaches. Only a strong cancer infrastructure can support, sustain and deliver discoveries made in the lab and the clinic to our children, who await a future without cancer.

Amy S. Langer is the Executive Director of the National Alliance of Breast Cancer Organizations (NABCO).

Founded in 1986 and based in New York City, NABCO is the country's leading non-profit resource for information and education about breast cancer, and a national force in patient advocacy. NABCO offers free breast cancer information to the public, survivors, medical professionals and the media -- heightening public awareness, empowering patients and connecting women with needed services. Reach NABCO at **(888) 80-NABCO**, or visit *www.nabco.org*.